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Understanding frailty: European policy makers' approaches to frailty screening and management.

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Abstract

Objective To elicit European healthcare policy makers' views, understanding and attitudes about the implementation of frailty screening and management strategies and responses to stakeholders' views.

Design Inductive thematic analysis of semi-structured qualitative interviews.

Setting European healthcare policy departments.

Participants Seven healthcare policy makers representing the European Union (N=2), UK (N=2), Italy (N=1), Spain (N=1) and Poland (N=1). Participants were sourced through professional networks and the European Commission Authentication Service website and were required to be in an active healthcare policy or decision making role.

Results Policy makers acknowledged that there was no simple solution to frailty management. Seven themes were identified: *awareness of the malleability of frailty; ownership of frailty; the need for a culture shift in care; barriers to a culture shift; cultural acceptance of an integrated care system; signposting adult care; and screening for and preventing frailty.* Findings recommend a multilateral campaign of raising awareness of the reversibility and preventability of frailty which targets professionals, policy makers and commissioners, as well as older adults. Policy makers emphasised the need to recognise frailty as a clinical syndrome but stressed that it should be managed via an integrated response to chronicity, ageing and dependency. This would require a culture shift in care and the integration of health and social care services. They noted that existing resources would need to be reallocated to develop and deliver frailty management and intervention services.

Conclusions Frailty is a syndrome which crosses traditional medical, discipline-specific boundaries. There is potential for it to be managed in a more integrated and person-centred manner, overcoming the cultural challenges associated with niche ownership within the healthcare system. There is also a need to raise its profile and develop a common understanding of its malleability, as well as consistency in how and when it is measured.

Strengths and Limitations of the Study

- To our knowledge, this is the first qualitative study with European policy makers on frailty.

- There were some differences in the professional roles of the participants, due to both the nature of the policy organisations in their respective countries and their professional background, for example some were clinically qualified while others were civil servants, although all had significant experience of working in frailty related roles.
- Nevertheless, it was possible to distil information and compare across accounts, which demonstrated a great number of similarities, irrespective of background and/or role.

Introduction

Frailty can be conceptualised as a multidimensional, clinical condition related to age, during which multiple physiological and psychological systems gradually lose their reserves, and individuals become less able to cope with daily stressors or acute illnesses. Older adults living with frailty are more vulnerable to adverse health outcomes, including institutionalisation and mortality, particularly when exposed to events such as a chronic disease diagnosis, an acute infection, or a fall. [1-3]

Research suggests that frailty is a dynamic process [4] and that there are opportunities along its pathway to transition out of, manage, and/or prevent its adverse consequences. [5-11] Early identification of frailty through screening programmes may provide the opportunity to identify pre-frail and frail individuals, and direct them to appropriate preventative health interventions to assist them to improve personal health and wellbeing, resulting in better management of societal healthcare costs. [12, 13]

Operational concepts of frailty have moved on from the earlier physiological phenotype [14, 15] or accumulation of deficits models. [16, 17] A broader multidimensional approach for measuring frailty [18, 19] has been adopted that also acknowledges psychological elements like wellbeing and quality of life, and social elements such as lack of social contacts or environmental and situational factors. [19-21] Embracing this approach, some studies have tested and noted success with multicomponent interventions. In varying combinations, interventions incorporating physical training, cognitive training, nutritional advice, and social support have resulted in significant improvements in frailty measures in community dwelling older adults. (e.g. 8, 22) and people in residential care homes. [23] (For reviews, see 24, 25). Such multicomponent interventions may also prevent future health risk and social isolation.

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Against this background of evidence for multicomponent interventions, this study forms the second phase of qualitative research with stakeholders on frailty prevention and screening. The first phase (26) aimed to explore how frailty prevention and screening would be accepted and adopted by European stakeholders, including frail and non-frail older adults, family caregivers, and health and social care professionals. Previously, older adults' and other stakeholders' views on frailty screening had not been sought. The findings from the first phase (26) demonstrated consistent results across the three countries involved (UK, Poland and Italy), and emphasised the need for a holistic approach to frailty care and early intervention. Participants raised the need for integrated and coordinated health and social care services, as well as personalised screening programmes and advocacy in the organisation of care. Central to all stakeholders was the significance and primacy of the psychological and social elements of frailty. Physical frailty was thought of as less malleable or preventable, but also of less importance provided individuals retained psychological resilience. Furthermore a meta-synthesis of qualitative evidence (25) highlighted the need to understand the acceptability of frailty screening among the general population of older adults, their caregivers, and other stakeholders, including the health and social care staff who may conduct assessments or deliver interventions, and to address the understanding of the malleability, reversibility or preventability of frailty.

This study completes the picture by exploring European healthcare policy makers' opinions on frailty and the feasibility of frailty screening programmes and healthcare interventions suggested by stakeholders during this earlier work, examining their responses to the findings of the first phase. (25, 26)

Method

This study is part of a larger programme, '*Frailty Management Optimisation through EIP-AHA Commitments and Utilisation of Stakeholders Input' (FOCUS)*, funded by the EU [Grant number 664367 FOCUS] (http://focus-aha.eu/en/home)(27). The methods used in this study conform to qualitative research reporting guidelines. (COREQ: 28)

Participants

Healthcare policy makers working at regional, national and European levels were purposively sampled. Participants were sourced through professional networks and ECAS (European Commission Authentication Service). They were required to be in an active healthcare policy

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and/or decision making role and have experience of frailty policy or frailty related healthcare policy. Ethical approval was provided by Aston University Research Ethics Committee (#844). Volunteers were given participant information sheets in English and understanding checked where interviews were conducted in a local language. Informed consent was received. In order to retain confidentiality, contributor's names, job titles, job descriptions, precise geographical locations and service names were anonymised (see Table 1).

Data collection

Individual interviews were conducted in English (except in Poland and Spain). Semi-structured interviews were conducted in person (PM01, PM06, and PM07) or over the telephone (PM02, PM03, PM04, and PM05). The interview schedule was defined in advance based on previous findings from stakeholder focus groups. [26] Before the interview, all participants were sent a summary of the findings of the previous study (Appendix 2). The most prominent themes from the previous findings were distilled into seven questions, with subordinate questions, to stimulate conversation (see Appendix 1). The same question list was used by all interviewers but within that, slightly different questions were asked of each policy maker, dependent on their area of expertise. Questions were not pilot tested. Interviews were facilitated by female researchers –psychologists (BDA, DPhil and HG, PhD) based in Italy and the UK respectively, General Practitioners (DK, MD, PhD and MBF, MD, PhD) in Poland and a project manager (EAJD, MSc) in Spain. All interviewers had previous experience in qualitative research. No personal information was relayed about the researchers to the participants. Given the status of participants in each country, their contributions represent a rich, contextualised understanding of healthcare policy perspectives on frailty and frailty management across Europe. The degree of commonality in responses suggests that saturation was achieved.

Data Analysis

Discussions were digitally audio recorded and transcribed verbatim in language of origin. Translations from the original language to English were reviewed by a native English speaker for syntactical structure and conceptual equivalence. Minor amendments were made to literal translations to ensure that participants' words were accessible and understandable. Amendments were checked with the translator to ensure that the original meaning had not been lost. Transcriptions were analysed by HG and RS using inductive thematic analysis.

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(29) Validity was protected by the use of transparent procedures and through constant exchange between interviewers (HG, BDA, EAJD, DK, TK) and analysts (HG, RS). A summary of findings, including verbatim data extracts was circulated to participants for comments. Six of the seven participants responded. They verified findings and stated that it captured the range of viewpoints successfully. Only minor amendments were made.

Patient Involvement

No patients were directly involved in this research. However, the views of previous focus group participants including frail and non-frail older adults were used to generate the interview schedule. (26)

Results
Sample Characteristics

Participants' characteristics are reported in Table 1. Limited information is provided to protect anonymity and retain confidentiality.

Table 1: Participant Information

Country	Title	Organisation	Role description
UK	Clinical Director	Secondary healthcare	Consultant physician with experience of unification of healthcare treatment protocols, medical interventions and sharing good practices.
Belgium	Acting Head of Unit	European Commission (DG Sanco)	Policy role in EU with experience of health strategy development and analysis.
UK	Clinical Lead for Integrated Care	National Government	Consultant physician with experience of policy development in integrated care and reshaping healthcare for older adults.
Luxembourg	Coordinator	European Commission (DG Sanco)	Policy role in public health with experience of implementing health programmes.
Italy	Managing Director	Directorate General Welfare	Policy and service planning with experience at a regional level.
Poland	Director	Regional Government	Policy role in regional government with experience of delivering integrated care, as well as technology and innovation in ageing.
Spain	Deputy Director	Regional Government	Physician. Policy Role at the Public Health Directorate.

To illuminate study findings, each theme is presented with example quotations. Quotations are attributed to each policy maker using a unique participant code.

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Awareness of the malleability of frailty

Policy makers' initial perception was that, despite increasing exposure to frail older adults, there was a lack of awareness around frailty; a "*knowledge gap*" (PM01) amongst general clinicians and allied health professionals. Policy makers raised the idea that frailty was not being effectively managed in the current acute care system and that whilst this could potentially be attributed to a variety of factors, a fundamental issue was a lack of understanding of the nature of frailty, and in particular its malleability.

> *"most of the professionals who work with adults and older people will be coming across frailty every day. They might not recognise what they can do about it but I think that they're aware of it as a challenge. I don't think they're fully aware of what the possibilities are." (*PM03)

A common thread throughout this and other policy makers' accounts was the growing challenge of the changing population demographics and the increasing numbers of health professionals who encounter frailty. Policy makers described a pressing need to raise the profile of frailty and consequently facilitate more effective management of frailty and frailty related conditions.

> *"I think fundamentally the key thing is that there should be a campaign about frailty, so that people start hearing that word more often and then they understand what frailty means. Simultaneously we need to have a dialogue with all the healthcare providers and key commissioners [...] At the healthcare professional level we need to create awareness, we need to train them to address frailty and also try to provide resources."* (PM01)

Furthermore, there were suggestions that clinical personnel should be better trained in recognising and managing frailty, specifically physicians, allied health professionals and healthcare policy makers including healthcare commissioners. The view here was that without raising the profile of frailty at all levels within the healthcare system and "*broadening the debate*" (PM02), little of significance could be achieved, in terms of allocating resources to frailty management and care. This was clarified by one policy maker:

> *"Currently, the awareness around frailty is poor, then whatever we talk about afterwards is not going to happen, until we address this primary deficiency."* (PM01)

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Although some policy makers demonstrated an understanding of the malleability of frailty, there were others who implied that frailty was a normal part of ageing and as such was not entirely preventable or reversible.

> "*There will be always frail people, but if we know what are the triggers for becoming frail, what are the diseases which then end up as, as a chronic disease which have frailty as a consequence. There, if you would know all this, you know, you should be acting in a very early stage for people to not get into the frailty stage, so in this sense, yes of course* [frailty is preventable] *but 100% [preventable], no*." (PM-04)

Despite some doubt about the malleability, reversibility and absolute preventability of frailty, which we acknowledge may be unachievable, the above extract demonstrates a strong conviction towards understanding the mechanisms of frailty in order to treat patients effectively.

Ownership of frailty

Policy makers' described that frailty management was currently owned by specialists.

> "*I think to a large extent the debate on frailty has been part of the geriatricians and some gerontologists also, so it's kind of a speciality issue.*" (PM02)

They suggested that ownership of frailty should be devolved from these specialists to a wider healthcare audience through an awareness raising campaign and training programme. For some, this meant categorising frailty as a clinical syndrome requiring intervention, like any other. Certainly, this would enable transparency in the management of this chronic condition and empower health professionals to extend their role in patient care. However, these ideas were limited, in that they were only associated with raising awareness and introducing expertise *within* the healthcare system. Other policy makers, specifically those involved in reforming or integrating their respective health and social care systems, took these views one stage further. They advocated that ownership should be extended to the wider community:

> "*I think that for decades or so, frailty has been very bio-medical and I think the real potential to unlock the opportunities is if we move out of that domain and see it as an area where there is huge potential from community capacity building, to community led interventions, social connectedness, that I think then brings it to a level of potential reversibility.*" (PM03)

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"And the health system … has to become more open, more inclusive, less deified, and it has to realise that the solution is not only on the "white coat" but this is a shared solution and there has to be a co-leadership or social co-production." (PM07)

Superficially, there appeared to be a dichotomy in beliefs about frailty management. On one hand, some policy makers appeared to support a greater medicalisation of frailty, a need for frailty to be recognised as an authentic clinical issue by medical professionals and treated as such. On the other, there were views that frailty should be demedicalised and that frailty management should be conceived of as an adaptation to life stages and be embraced as a societal issue with ownership devolved to a wider societal network. On further examination, it was determined that these views were not mutually exclusive but rather described a spectrum of ownership of frailty, representing different degrees of enablement and empowerment for frail older adults.

Conducting training and developing knowledge in healthcare professionals ensures that frail older adults are treated with compassion and dignity, and crucially, enables them to find support to make informed choices about their own health and healthcare. Certainly, several policy makers endorsed the view that patient input and empowerment was important within care systems.

"I think that the issue here is that we should listen more to the affected people and we must develop more protocols, guidelines, programmes with the affected people and not exclusively from the expert, professional or public health opinion." (PM07)

Ownership has implications for both costs and treatment. Given ongoing changes in population demographics, reducing the burden on the healthcare system by involving the wider community provides a financially sustainable solution. Also, given the multicomponent, bio-psycho-social nature of frailty, a purely medical/physical approach to frailty may fail to address some or all of the cognitive and/or social components associated with the condition.

In summary, this theme challenges the role of the hospital and specialists as the dominant force in frailty care. It provides an opportunity for medical professionals, specifically specialists, to share ownership of frailty, certainly with other healthcare professionals in the short term and also to actively engage with the wider community. In doing this, a culture shift

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in care could be facilitated and older adults empowered to take greater control of their later life journey, which will be discussed next.

A culture shift in care

Participants judged that there was no simple solution to the frailty challenge and that there was no single body responsible for leading a culture change.

> "*It's all stakeholders. There's no one person that owns this. There's no one sector that owns it. There's no one group of professionals that owns it so it's got to be across public sector, a cross-government kind of approach.*" (PM03)

Shifts in ownership of frailty would constitute a significant shift in the prevalent models of care. Policy makers were aware that the current model of acute care was not effective in managing complex, chronic conditions such as frailty and that a culture shift was required to adapt to the changing needs of the population.

> "*I think that it is increasingly consensual that our current health care models are not so conducive to looking at this sort of complex cases. I mean you have a lot of, increasingly you hear about, issues about multimorbidity for instance but still our healthcare systems are geared to single chronic diseases.*" (PM02)"

There was a recognition that frailty and frailty management are complex issues involving many stakeholders and numerous components. This was a view supported by other policy makers who described frailty as a "*puzzle*" (PM01). Participants noted the multiplicity of stakeholders involved in the creation of a 'new' culture and suggested that in order to facilitate change, a multilateral approach to raising awareness, from the 'bottom up' (general public) and the 'top down' (healthcare commissioners) would be necessary.

In terms of delivery of a more appropriate system, policy makers described a model of integrated and person-centred care in which frail older adults are treated as a whole, rather than as a fragmented collection of illnesses. They also described a system that would empower older adults to reduce their dependency on others, and ultimately conserve resources.

> "*If somebody needs assistance in washing and dressing we tend to enable them, whatever their daily needs but we are not enabling them to make themselves more capable of doing that. I think if we were addressing frailty it would get us to that point*

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and in fact, it might save, eventually, in the long term, some of the costs associated with caring because at least, even a small proportion get self-caring, is still beneficial." (PM01)

There was also a warning by one policy maker that medicalising frailty and singling it out as a clinical syndrome would disrupt recent progress in care integration.

"*I think that one of the biggest challenges and the biggest risks is that if you put this into a frailty box. I think that this has got to be done in the context of this is about older people, this is about later life, this is about people centred integrated care and support. I think if we try to make it something that is different from what we've been talking about for the last ten, fifteen years around chronic disease, we'll fail.*" (PM03)

Supporting this and developing it further was another policy maker's "*salutogenic*" (PM07) perspective addressing cultural norms about health and the way in which contemporary society focuses on the absence of health or the presence of an acute/chronic condition. Within this idea, they described how an experience of frailty could potentially be embraced as a way of opening up a range of possibilities, interactions and opportunities, particularly within the community, "*a social prescription*" (PM07). In their thoughts about care integration, they spoke about a concept of citizenship, a social movement, "carezenship" as a marker of an advanced society, an advanced citizenship, one in which citizens take care of themselves (both on a personal and societal level) and learn to value care. However, they acknowledged that this would be a challenge.

"We are asking a lot of ourselves to reorient programmes and interventions with a salutogenic approach, and give prominence to people, to the people themselves, rather than the scope of needs that generate demand for services, and professionals to look after needs, and also to create health based on assets, on these resources we all have." (PM07)

Barriers to a culture shift

Policy makers described an integrated model of care as appealing in theory. They provided some evidentiary support, notably from pilot schemes, but they acknowledged that it would take time and thought to integrate into existing systems.

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> "*It's a bit of a long game and I think progress that has been made is now becoming even more challenging with the current fiscal environment. So, yes, we know it's the application of the chronic care model for long term conditions but doing that through a functional, a people-centred, integrated and functional lens, absolutely we know what we need to do, we just need to do it.* (PM03)

This latter extract raises potential barriers to an integrated and truly democratic healthcare system: there is a time element, an acknowledgement that this is a "*long game*" (PM03) and that change management is a lengthy process; there is a need to be mindful of finances and resourcing issues; there is a need to take action, to implement the system or actually "*do it*" (PM03); and there is a need to focus on patients' autonomy.

Despite acknowledging the difficulties and lack of funding for new projects in the current environment of austerity, policy makers indicated that finances and resources were available and could potentially be reallocated to support a different system.

> "*So, can this still be deliverable? The answer is yes but it needs a great deal of commitment, a great deal of fresh thinking to see how we are currently utilising our resources and see how we can change it to fit into this pathway and … we've already got nutritionists, we've already got physiotherapists, we've already got occupational therapists and physical activity experts, but currently the way we utilise them is different and what we need to do is see whether there could be changes in the way they actually deliver their service with frailty as an underlying theme.*" (PM01)

This extract emphasises the need to do things differently, to think creatively and to *"rewire and use [assets] differently"* (PM03), in order to better manage complex and chronic care needs. There is a sense that change is both possible and necessary, and that resources are available to facilitate this:

> "*Since 2014 I would say we have had every year sizeable envelopes from different programmes from the [commissioner]. So the finance is available……so there has consistently been money for this even when it's not called, that it's not for frailty.*" (PM02)

Another challenge for resourcing is the fact that frailty is often subsumed within other remits and is viewed within a subset of many other chronic diseases of older adults. In fact, there was a strong sense from policy makers that frailty could not be viewed in isolation or

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"*disconnected from the wider conversation about managing chronicity and complexity in care systems*" (PM03) and therefore should not be funded separately. It is important to note though, that policy makers state that a focus on frailty is required.

Cultural acceptance of an integrated care system

The complexities surrounding change management in large systems and institutions, as well as issues of cultural acceptance of a new way of working were described.

> *"I think this* [acute healthcare model] *is a problem, not just in* [region name] *but all over the world…I think it will be a very slow process.…I expect this process will take probably five to ten years before the culture of professionals will be ready because our doctors, our General Practitioners, our specialists and also social care workers are not trained to change their way." (PM05)*

Indeed, the power transfer from senior clinicians to a wider range of potentially less well qualified staff in a truly democratic care pathway, implied in this extract, was an issue raised by a number of policy makers. Policy makers noted that senior clinicians may be reluctant to involve less well qualified people in decision making processes.

> *"What is integrated care? What is person centred care? What is joint decision making? …it would, in several systems probably need a radical, a new thinking of… not this, "I'm the doctor, I know what's good for you, this is what you're going to do" but a change in the doctor-patient relationship and also in the relationship among the different health personnel. You know, if suddenly the social carer has the same say in a discussion around a specific patient as the medical doctor."* (PM04)

Policy makers described cultural issues of medical hierarchy and physician dominance in health care, where power is exercised through the professional autonomy of doctors. There are issues here about the ability of doctors to treat allied health professionals and other stakeholders, for example carers, as equal counterparts in the care of frail adults. Further, there are issues of trust and reluctance on the part of the doctors to transfer power, knowledge and ownership of frailty management in a more democratic system; equally there may be reluctance on the part of other stakeholders to accept those responsibilities; thus resulting in fractures in care provision. Notwithstanding these cultural challenges, policy makers were optimistic and believed that barriers could be overcome given sufficient time and training.

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Several policy makers were keen that any new frailty management system should be woven into a wider network of healthy ageing issues and delivered as a programme styled as "*living well for longer*". (PM03). The aim of this was to standardise approaches to multimorbidity and chronic disease, i.e. to have the same pathway for all, but also to overcome the negative connotations and language associations with frailty.

> "*I think we're probably stuck with a fairly negative connotation from frailty, sounds as if it's something that means people are helpless, nothing you can do, whereas if we slip language and put the focus on ageing well, active and healthy ageing, living you know, living more positive fulfilling lives, then people could hang on to that, what's not to like about that?"* (PM03)

Signposting adult care

Stakeholders in the first phase described difficulties accessing care and navigating overly complex care systems. To overcome this, they expressed the need for an official "wellbeing coordinator". This suggestion for a new health visitor style role, as an advocate, monitor and source of information, was not supported by policy makers.

Some policy makers suggested that the role was unnecessary as the family doctor or GP could act as a care navigator.

> "*I would like to think that a good General Practitioner, who has good understanding of frailty, can be themselves the coordinator, we don't need a separate person.* (PM01)

Others suggested that GPs are already overburdened and that there are potentially more suitable people to take on this task.

> "*Actually, it doesn't need to be the GP, the GP might not be the best placed person for that individual. It might be the mental health nurse, it might be the social worker, it might be the OT* [occupational therapist], *it might be community connector."* (PM03)

Policy makers also raised the idea that new services, such as a wellbeing coordinator should be elective rather than prescriptive, which might also assist in controlling care costs.

> "*So, I think the one size fits all is definitely not the way to go and personalised care, where the patient only receives the treatment that she really needs, maybe in the end*

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this would actually be cost effective for the health system if you don't get everything just because a protocol foresees it." (PM04)

To summarise, the proposed new role of the wellbeing coordinator was not supported. However the policy makers acknowledged that an enabled person in an existing role, a personal *navigator* is required to help older adults and their caregivers to access appropriate services.

Screening for and preventing frailty

Policy makers were receptive to the idea of screening for frailty so long as it initiated a proactive consultative programme of care and interventions, a view which resonated with focus group members in the first phase of research. One policy maker (PM07) made the point that screening was simply another method of "*medicalising*" frailty and categorising a life stage. Despite doubts about the preventability and reversibility of frailty, there was a strong belief in the power of screening as a tool for effectively targeting those most in need of healthcare services and interventions, and directing resources accordingly.

"If you are able to detect this health problem early and to know that you have the right measures to apply them and that they will really make improvements in life expectancy, in quality of life, then the benefit is really there." (PM07).

One participant raised concerns about the viability of frailty prevention interventions in an older, chronically ill population, i.e. whether interventions are cost effective and beneficial.

"*Screening is necessary. Is it viable? Most likely for the system, on balance, yes. Why? The problem of intervention in the case of these people, if we look to the future, must be focused on their specific health needs. So it is good to know which patients they are so we do not undertake unnecessary medical interventions. If a patient comes to a specialist who does not recognise frailty, they will want to cure the patient. So the question is, if frailty cannot be cured, are those interventions necessary from a medical standpoint?"* (PM06)

The perception that frailty is untreatable is also of interest, although this was not shared by all participants. Irrespective, there was an overwhelmingly positive view from policy makers that screening *followed by interventions* are worthwhile:

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"I would really only support screening for frailty if it was linked with the kind of interventions that can make a difference. Otherwise, why are we doing the screening programme? It's about human values as much as pounds." (PM03)

Policy makers were also concerned with wider issues, the practicalities of screening and the complexity of screening tools.

"Any tool that is complex or that has multiple steps or requires quite a lot of in depth assessment might be quite difficult to perform as a screening tool, purely because the numbers we would be dealing with are going to be huge. We wouldn't have the resource (PM01)

There was a general consensus that a "*simple and easily reproducible*" (PM01) or "*straightforward*" (PM02) tool was required to minimise the resource and labour implications for health services and key professionals.

The affordability of population screening programmes was not a primary concern. Policy makers agreed that there were ways of reducing screening costs through targeting strategies such as algorithms and e-Health or self-assessment systems. Of more concern were the matters of when screening would occur and who would undertake it. One policy maker had a clear opinion that it should not be undertaken by General Practitioners.

"and, who would be screening for frailty? You know, the GP? I don't know, is that another thing you want to burden on GPs? Did you speak to GPs about that? You know, we are putting so much on them, you know literally everything is on the GP in this regard, everything." (PM04)

Policy makers were mindful of screening at "*key transition points*" (PM03) in people's lives: including instances of acute illness, prescription review, bereavement, and moving home/care setting. The view here was that screening and intervening at these critical points can significantly affect the incidence of adverse outcomes such as institutionalisation and dependency. Reverting back to the idea of an integrated and personalised system of care, there was also an understanding that an individual-specific "*care navigator*" (PM03) would be present at the time of screening.

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Discussion

The data gathered have enabled us to consider which issues need to be addressed to assist in frailty management, screening and prevention programmes. We identified a *knowledge gap* regarding frailty and the need to raise awareness of frailty and the treatability of frailty throughout the medical profession through improved training and research. We also identified the need for frailty to be recognised as a clinical syndrome but managed within a broader remit of *healthy ageing* in the community.

Despite evidence to the contrary, our analysis found that some policy makers, as well as other stakeholders, believe that frailty is not preventable or amenable to intervention. Since the effectiveness of any frailty management or screening programme relies on the prioritisation and allocation of resources and labour, this may lead to inequality in service provision across different jurisdictions. Further, there is a danger that screening programmes in these areas will classify older adults as frail or pre-frail, identifying those who would benefit from early intervention but then fail to implement appropriate preventative treatments.

Policy makers recognised the difficulties associated with managing frailty and the need to apply creative solutions to better organise and redeploy existing services, resources, skills and knowledge sets to manage complex and chronic care needs.

We noted that policy makers placed value on the development of an integrated and person-centred system of care, involving a care navigator, and while this idea is to some extent in its infancy, there was a strong sense that this was the preferred route. Certainly this system is in line with the Chronic Care Model (30, 31) which has been shown to improve patient care and result in improved outcomes in chronic conditions (32).

We confirmed the views of previous stakeholders (26) that screening for frailty must have an outcome or specific purpose; and that outcomes are absolutely essential from a human and moral perspective. We have also identified that there must be an individually negotiated, person-centred and transparent care pathway available after screening for all frail older adults and that this pathway must be sufficiently flexible to adapt to individuals' needs, whether those are physical, cognitive or social. Underlying this culture shift in older adult care is the need to empower people to make informed choices about their own health and healthcare, but such empowerment requires high levels of perceived behavioural control (33) and self-efficacy (self confidence in one's own ability to achieve a particular task, e.g., 34, 35). In this

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case, believing that frailty is preventable and malleable provides the basis for that self-efficacy; the self-confidence to take charge of one's frailty prevention pathway is dependent on the belief that it is possible. (33) Furthermore, self-efficacy requires ownership; older adults must take ownership of their frailty prevention pathway to engage in it as an active agent. This self-advocacy in turn depends upon healthcare providers who are genuinely person-centred and able to enter into the true spirit of concordance, that is, a negotiated consultation which facilitates informed and collaborative decision making. (36) To achieve this, a psychological behaviour change intervention aimed at healthcare providers may be useful, to shift their approach from advice giving, which comes naturally to them and has been rehearsed for many years, towards a collaborative consultation which fosters authentic patient empowerment (37) and takes older adults' freedom of choice seriously. From there, person-centred care, concordance, and the phenomenon of "carezenship" (PM07) become a conceivable possibility, albeit a possibility that will require long term focus and systemic investment to achieve.

Conclusions and implications for clinicians and policy makers

Frailty is a syndrome which crosses traditional medical, discipline-specific boundaries. Our findings recommend a multilateral campaign of raising awareness of the malleability and preventability of frailty which targets health and social care professionals, healthcare policy makers and commissioners as well as older adults themselves. The aim of this would be to shift attitudes about the inevitability of frailty and overcome some of the cultural challenges associated with niche ownership within the healthcare system, but also to support the idea of integrated care for older adults. The policy makers also recognised the need to better signpost older adult services and recommended a personal *navigator* to help older adults and their family caregivers to access appropriate interventions and services: this may be the GP, a social worker or a community volunteer, but the view was that a new role, that of a wellbeing coordinator, was not justified.

What is already known on this topic

- Some studies suggest that frailty is malleable and as such there are opportunities to transition out of, or manage and/or prevent its adverse consequences.
- European stakeholders (robust and frail older adults, health and social care

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professionals, and family caregivers) believe that physical frailty is less malleable and/or preventable than psychological or social aspects of the condition.

- Stakeholders would prefer an integrated and coordinated health and social care system with personalised frailty screening and advocacy in the organisation of care.

What this study adds

- This is the first study to review policy makers' views on frailty management and screening programmes, from six European countries.
- Our findings demonstrate a '*knowledge gap*' across medical professionals and wider society relating to the reversibility, malleability and preventability of frailty.
- Policy makers thought that frailty should be recognised as a clinical syndrome which encompasses psychological and social features, and should therefore be managed within a person-centred and integrated care plan.
- Our findings suggest that episodic care is no longer deemed appropriate for frail older adults and that a move towards holistic and integrated care is both envisaged by policy makers, and in progress.
- Frailty screening should only be conducted where it initiates a pro-active consultative programme of care.

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All authors are guarantors and affirm that the manuscript is an honest, accurate, and transparent account of the study being reported, and that no important aspects of the study have been omitted; and that any discrepancies from the study as planned have been explained.

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Appendix 1

Questions for Policy Makers:

This is a guide as to the topics that should be covered, but participants are be free to add other things they think are important.

1. **What do you understand by the term "frailty"**

   Subordinate questions (to encourage fullness of response if necessary)

   (i)   What do you think are the likely causes of frailty?

2. **To what extent do you think frailty can be addressed in the population?**

   (i)   Do you think there are ways we could prevent people from becoming frail?

   (ii)   Do you believe that frailty is treatable or preventable (malleable)?

   (iii)   Do you think there are opportunities to influence frailty status by means of early identification and management through lifestyle and other interventions?

   (iv)   How can we raise awareness of the malleability of frailty among professionals and across society generally to encourage a cultural shift in views on frailty?

3. **To what extent do you think frailty can be addressed in the population?**

4. **Do you think that screening for frailty in older adults is worthwhile?**

   (i)   What are the barriers to screening as you see them?

   (ii)   What are the benefits to screening as you see them?

   (iii)   In our research, participants raised a number of challenges associated with frailty screening, the form that they suggested, one which was consultative, sensitive, and which leads to personalized care would be expensive for health and social care systems to implement. To what extent do you believe screening for frailty in this manner would be possible?

   - Financially?
   - Practically?

5. **Do you think that a model of acute care is suitable or unsuited to patients with complex needs (i.e. frailty)?**

   (i)   how can care pathways be better organised and delivered in order to ensure that the needs of people with multiple risk factors are fully addressed?

(ii)   (Prompts: reliable holistic assessment, multidisciplinary care planning, care co-ordination, improving communication between patient, family members and professionals, continuity of care, access to specialists and diagnostics)

(iii)   Participants also made suggestions about how frailty prevention services could be improved to support older adults, e.g. by engaging them in preventative strategies such as stimulating cognitive activity, personalised exercise plans, greater social engagement, in order to build resilience; and by the development of an advocacy service to help older adults and their family caregivers to access services. A care coordinator model or adult health visitor type role was suggested as a bridge between health and social care services. To what extent do you believe that these changes would be possible?

(iv)   What difficulties would you expect if treatments or interventions (e.g., such as exercise training) for frailty were to be introduced more widely? Do you think that is a good idea? What benefits would that have? What might be the problems with that (e.g., costs, resources, implementation)?

6. **What type of legislation, regulation, standards, guidelines or measures do you believe would be required to ensure that a frailty prevention/management system can be fully supported?**

(i)   Who do you believe are the key individuals who make decisions in the areas of frailty care/prevention/management and funding?

(ii)   What do you perceive as the main challenges in translating frailty prevention/management policy to practice?

7. **Is frailty prevention/management a priority for your department?**

(i)   What sort of work is being done by <your department> to ensure that an agenda of care is being implemented to prevent/manage/reverse frailty?

(ii)   Has your work/the work of <your department> influenced legislation, regulations, policy, programming or procedures? If so, where/when/how?

(iii) Are finances available to specifically address frailty issues?

a. If so, how is funding distributed? Centralised vs decentralised? And prioritised?

(iv)   Where is the money spent now?

a. Prompts: Care or preventative care?

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(v)   Have you involved older adults (frail or otherwise) in your public discussions

or policy making?

8. How can training and Continuous Professional Development be improved to

assist in frailty prevention?

(i)   Do you see a role for telecare or internet based programmes in prevention or

management of frailty?

(ii)   Do you know any e-health services /applications which can be used with

benefit by frail patients?

(iii)   How can potential services be made accessible for all?

a. Prompts, e.g., outside office hours, workplaces, community settings, faith

centres, digital services, range of languages and culturally acceptable

styles.

9. Is there anything else you'd like to add?

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Appendix 2

Summary

Understanding frailty: meanings and beliefs about screening and prevention across key stakeholder groups in Europe

This interview is to elicit the response of policy and decision makers to a summary of what other people involved in the context of frailty have said about it, with an emphasis on screening, management, personal and care strategies.

Objectives were to explore different stakeholders' understandings of frailty; the meaning of the condition and their beliefs and attitudes towards the malleability of frailty in view of screening and prevention programmes.

Semi-structured focus group and individual interviews were conducted in three EU countries (Italy, Poland, UK) with five groups of stakeholders – frail and non-frail older adults, family caregivers, and health and social care professionals. An inductive thematic analysis was conducted on transcribed interviews.

Four themes were identified:

·   Interdependence between the physical and the psychological in frailty,

·   living with frailty in the social world,

·   the need for a new kind of care,

·   screening for and preventing frailty.

Findings emphasized the need for earlier intervention for frailty prevention services and an integrated approach to frailty care. Central to all stakeholder groups was the significance of psychological components and social environment alongside the physical elements of frailty and frailty prevention, with this identified by many as making the difference between resilience in the context of physical impairment, and dependence and poor quality of life.

The findings concluded that support and care for older adults and their family caregivers needs to be accessible and coordinated. Interventions to prevent frailty need to encompass a social dimension to help older adults maintain a sense of self while also building physical and psychological resilience.

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Manuscripts

Understanding frailty: a qualitative study of European healthcare policy makers' approaches to frailty screening and management.

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Abstract

Objective To elicit European healthcare policy makers' views, understanding and attitudes about the implementation of frailty screening and management strategies and responses to stakeholders' views.

Design Thematic analysis of semi-structured qualitative interviews.

Setting European healthcare policy departments.

Participants Seven European healthcare policy makers representing the European Union (N=2), UK (N=2), Italy (N=1), Spain (N=1) and Poland (N=1). Participants were sourced through professional networks and the European Commission Authentication Service website and were required to be in an active healthcare policy or decision making role.

Results Seven themes were identified. Our findings reveal a "knowledge gap", around frailty and *awareness of the malleability of frailty,* which has resulted in restricted *ownership of frailty* by specialists. Policy makers emphasised the need to recognise frailty as a clinical syndrome but stressed that it should be managed via an integrated and interdisciplinary response to chronicity and ageing. That is, through social co-production. This would require a *culture shift in care* with redeployment of existing resources to deliver frailty management and intervention services. Policy makers proposed *barriers to a culture shift,* indicating a need to be innovative with solutions to empower older adults to optimise their health and wellbeing, while still fully engaging in the social environment. The *cultural acceptance of an integrated care system* theme described the complexities of institutional change management, as well as cultural issues relating to working democratically, while in *signposting adult care*, the need for a personal navigator to help older adults to access appropriate services was proposed. Policy makers also believed that *screening for frailty* could be an effective tool for frailty management.

Conclusions There is potential for frailty to be managed in a more integrated and person-centred manner, overcoming the challenges associated with niche ownership within the healthcare system. There is also a need to raise its profile and develop a common understanding of its malleability among stakeholders, as well as consistency in how and when it is measured.

Strengths and Limitations

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- To the best of our knowledge, this is the first qualitative study with European healthcare policy makers to focus on the implementation of frailty screening and management strategies.
- Use of semi-structured interviews allowed us to collect detailed insights into policy makers' views, understanding and attitudes towards frailty management, screening and prevention programmes.
- The main limitation is that the sample size is unavoidably small. There are only a few policy makers in senior healthcare positions within the European Commission or at a senior level nationally, and thus, as elites, the potential pool of participants is itself very small.

Introduction

Frailty can be conceptualised as a multidimensional, clinical condition related to age, during which multiple physiological and psychological systems gradually lose their reserves, and individuals become less able to cope with daily stressors or acute illnesses. Older adults living with frailty are more vulnerable to adverse health outcomes, including institutionalisation and mortality, particularly when exposed to events such as a chronic disease diagnosis, an acute infection, or a fall. (1-3)

Research suggests that frailty is a dynamic process (4) and that there are opportunities along its pathway to transition out of, manage, and/or prevent its adverse consequences. (5-11) Early identification of frailty through screening programmes may provide the opportunity to identify pre-frail and frail individuals, and direct them to appropriate preventative health interventions to assist them to improve personal health and wellbeing, resulting in better management of societal healthcare costs. (12, 13)

Operational concepts of frailty have moved on from the earlier physiological phenotype (14, 15) or accumulation of deficits models. (16, 17) A broader multidimensional approach for measuring frailty (18, 19) has been adopted that also acknowledges psychological elements like wellbeing and quality of life, and social elements such as lack of social contacts or environmental and situational factors. (19-21) Embracing this approach, some studies have tested and noted success with multicomponent interventions. In varying combinations, interventions incorporating physical training, cognitive training, nutritional advice, and social support have resulted in significant improvements in frailty measures in community dwelling

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older adults (e.g. 8, 22) and people in residential care homes. (23) (For reviews, see 24, 25). Such multicomponent interventions may also prevent future health risk and social isolation.

Against this background of evidence for multicomponent interventions, this study forms the second phase of qualitative research with stakeholders on frailty prevention and screening. The first phase (26) aimed to explore how frailty prevention and screening would be accepted and adopted by European stakeholders, including frail and non-frail older adults, family caregivers, and health and social care professionals. Previously, older adults' and other stakeholders' views on frailty screening had not been sought. The findings from the first phase (26) demonstrated consistent results across the three countries involved (UK, Poland and Italy), and emphasised the need for a holistic approach to frailty care and early intervention. Participants raised the need for integrated and coordinated health and social care services, as well as personalised screening programmes and advocacy in the organisation of care. Central to all stakeholders was the significance and primacy of the psychological and social elements of frailty. Physical frailty was thought of as less malleable or preventable, but also of less importance provided individuals retained psychological resilience. Furthermore a meta-synthesis of qualitative evidence (25) highlighted the need to understand the acceptability of frailty screening among the general population of older adults, their caregivers, and other stakeholders, including the health and social care staff who may conduct assessments or deliver interventions, and to address the understanding of the malleability, reversibility or preventability of frailty.

This study completes the picture by exploring European healthcare policy makers' opinions on frailty and the feasibility of frailty screening programmes and healthcare interventions suggested by stakeholders during this earlier work, examining their responses to the findings of the first phase. (25, 26)

Method

This study is part of a larger programme, '*Frailty Management Optimisation through EIP-AHA Commitments and Utilisation of Stakeholders Input' (FOCUS)*, funded by the EU [Grant number 664367 FOCUS] (http://focus-aha.eu/en/home)(27). The methods used in this study conform to qualitative research reporting guidelines. (COREQ: 28)

Participants

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Healthcare policy makers working at regional, national and European levels were purposively sampled. Participants were sourced through professional networks and ECAS (European Commission Authentication Service). They were required to be in an active healthcare policy and/or decision making role and have experience of frailty policy or frailty related healthcare policy. Two participants did not respond to a request for interview, no reason was provided. Ethical approval was provided by Aston University Research Ethics Committee (#844). Volunteers were given participant information sheets in English and understanding checked where interviews were conducted in a local language. Informed consent was received. In order to retain confidentiality, contributor's names, job titles, job descriptions, precise geographical locations and service names were anonymised (see Table 1).

Data collection

Individual interviews were conducted in English (except in Poland and Spain) and lasted between 30 and 90 minutes. Semi-structured interviews were conducted in person (UK and Poland), over the telephone (UK, Luxembourg, Belgium, and Italy) or by video conference (Spain). Only interviewers and participants were present. The interview schedule was defined in advance based on previous findings from stakeholder focus groups. [26] Before the interview, all participants were sent a summary of the findings of the previous study (Appendix 1). The most prominent themes from the previous findings were distilled into seven questions, with subordinate questions, to stimulate conversation (see Appendix 2). The same question list was used by all interviewers but within that, slightly different questions were asked of each policy maker, dependent on their area of expertise. Questions were not pilot tested. At interview, we a) made clear the stakeholders' opinions and needs to policy makers; b) asked them about the feasibility of the implementation of the needs and suggestions that had emerged during stakeholder discussion and c) collected policy makers' possible proposals to better address stakeholders' concerns.

Interviews were facilitated by female researchers –psychologists (BDA, DPhil and HG, PhD) based in Italy and the UK respectively and a General Practitioner (DK, MD, PhD) in Poland. The interview in Spain, was conducted by a male senior professor of obstetrics and gynaecology with a female project manager (AC, MD and EAJD, MSc). All interviewers had previous experience in qualitative research. No previous relationships existed between interviewers and participants and no personal information was relayed about the researchers to the participants except in Italy, where the interviewer was known to the policy maker.

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Given the status of participants in each country, their contributions represent a rich, contextualised understanding of healthcare policy perspectives on frailty and frailty management across Europe.

Data Analysis

Discussions were digitally audio recorded and transcribed verbatim in language of origin. Translations from the original language to English were reviewed by a native English speaker for syntactical structure and conceptual equivalence. Minor amendments were made to literal translations to ensure that participants' words were accessible and understandable. Amendments were checked with the translator to ensure that the original meaning had not been lost. Transcriptions were analysed by HG and RS using thematic analysis (29) with coding generated both inductively and deductively. The process of inductive coding involved thorough and repeated reading of transcripts to develop a set of preliminary themes. Notes were made independently by analysts to highlight issues raised by policy makers, and a search for patterns was conducted. Codes were assigned, collated and compared within and across transcripts. Themes were then developed through discussion and further independent interpretative work until consensus was reached within the wider team. Codes were also devised deductively from questions asked during the interview process and grouped into themes. Finally, concepts were clustered and synthesized into the interpretation presented here. Validity was protected by the use of transparent procedures and through constant exchange between interviewers (HG, BDA, EAJD, DK, TK) and analysts (HG, RS). A summary of findings, including verbatim data extracts was circulated to participants for comments. Six of the seven participants responded. They verified findings and stated that it captured the range of viewpoints successfully. Only minor amendments were made.

Patient Involvement

No patients were directly involved in this research. However, the views of previous focus group participants including frail and non-frail older adults were used to generate the interview schedule. (26)

Results
Sample Characteristics

Participants' characteristics are reported in Table 1. Limited information is provided to protect anonymity and retain confidentiality.

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Table 1: Participant Information

Country	Title	Organisation	Role description
UK	Clinical Director	Secondary healthcare	Consultant physician with experience of unification of healthcare treatment protocols, medical interventions and sharing good practices.
Belgium	Head of Unit	European Commission (DG Santé)	Policy role in EU with experience of health strategy development and analysis.
UK	Clinical Lead for Integrated Care	National Government	Consultant physician with experience of policy development in integrated care and reshaping healthcare for older adults.
Luxembourg	Programme Coordinator	European Commission (DG Santé)	Policy role in public health with experience of implementing health programmes.
Italy	Managing Director	Directorate General Welfare	Policy and service planning with experience at a regional level.
Poland	Director	Regional Government	Policy role in regional government with experience of delivering integrated care, as well as technology and innovation in ageing.
Spain	Deputy Director	Regional Government	Physician. Policy Role at the Public Health Directorate.

To illuminate study findings, each theme is presented with example quotations. Quotations are attributed to each policy maker using a unique participant code.

Awareness of the malleability of frailty

Policy makers' initial perception was that, despite increasing exposure to frail older adults, there was a lack of awareness around frailty; a "*knowledge gap*" (PM01) amongst general clinicians and allied health professionals. Policy makers raised the idea that frailty was not being effectively managed in the current acute care system and that whilst this could potentially be attributed to a variety of factors, a fundamental issue was a lack of understanding of the nature of frailty, and in particular its malleability.

> *"most of the professionals who work with adults and older people will be coming across frailty every day. They might not recognise what they can do about it but I think that they're aware of it as a challenge. I don't think they're fully aware of what the possibilities are." (*PM03)

A common thread throughout this and other policy makers' accounts was the growing challenge of the changing population demographics and the increasing numbers of health

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professionals who encounter frailty. Policy makers described a pressing need to raise the profile of frailty and consequently facilitate more effective management of frailty and frailty related conditions.

> *"I think fundamentally the key thing is that there should be a campaign about frailty, so that people start hearing that word more often and then they understand what frailty means. Simultaneously we need to have a dialogue with all the healthcare providers and key commissioners [...] At the healthcare professional level we need to create awareness, we need to train them to address frailty and also try to provide resources."* (PM01)

Furthermore, there were suggestions that clinical personnel should be better trained in recognising and managing frailty, specifically physicians, allied health professionals and healthcare policy makers including healthcare commissioners. The view here was that without raising the profile of frailty at all levels within the healthcare system and "*broadening the debate*" (PM02), little of significance could be achieved, in terms of allocating resources to frailty management and care. This was clarified by one policy maker:

> *"Currently, the awareness around frailty is poor, then whatever we talk about afterwards is not going to happen, until we address this primary deficiency."* (PM01)

Although some policy makers demonstrated an understanding of the malleability of frailty, there were others who implied that frailty was a normal part of ageing and as such was not entirely preventable or reversible.

> *"There will be always frail people, but if we know what are the triggers for becoming frail, what are the diseases which then end up as, as a chronic disease which have frailty as a consequence. There, if you would know all this, you know, you should be acting in a very early stage for people to not get into the frailty stage, so in this sense, yes of course* [frailty is preventable] *but 100% [preventable], no.*" (PM04)

Despite some doubt about the malleability, reversibility and absolute preventability of frailty, which we acknowledge may be unachievable, the above extract demonstrates a strong conviction towards understanding the mechanisms of frailty in order to treat patients effectively.

Ownership of frailty

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Policy makers' described that frailty management was currently owned by specialists.

> *"I think to a large extent the debate on frailty has been part of the geriatricians and some gerontologists also, so it's kind of a speciality issue."* (PM02)

They suggested that ownership of frailty should be devolved from these specialists to a wider healthcare audience through an awareness raising campaign and training programme. For some, this meant categorising frailty as a clinical syndrome requiring intervention, like any other. Certainly, this would enable transparency in the management of this chronic condition and empower health professionals to extend their role in patient care. However, these ideas were limited, in that they were only associated with raising awareness and introducing expertise *within* the healthcare system. Other policy makers, specifically those involved in reforming or integrating their respective health and social care systems, took these views one stage further. They advocated that ownership should be extended to the wider community:

> *"I think that for decades or so, frailty has been very bio-medical and I think the real potential to unlock the opportunities is if we move out of that domain and see it as an area where there is huge potential from community capacity building, to community led interventions, social connectedness, that I think then brings it to a level of potential reversibility."* (PM03)

> *"And the health system … has to become more open, more inclusive, less deified, and it has to realise that the solution is not only on the "white coat" but this is a shared solution and there has to be a co-leadership or social co-production."* (PM07)

Superficially, there appeared to be a dichotomy in beliefs about frailty management. On one hand, some policy makers appeared to support a greater medicalisation of frailty, a need for frailty to be recognised as an authentic clinical issue by medical professionals and treated as such. On the other, there were views that frailty should be demedicalised and that frailty management should be conceived of as an adaptation to life stages and be embraced as a societal issue with ownership devolved to a wider societal network. On further examination, it was determined that these views were not mutually exclusive but rather described a spectrum of ownership of frailty, representing different degrees of enablement and empowerment for frail older adults.

Conducting training and developing knowledge in healthcare professionals ensures that frail older adults are treated with compassion and dignity, and crucially, enables them to find

support to make informed choices about their own health and healthcare. Certainly, several policy makers endorsed the view that patient input and empowerment was important within care systems.

> *"I think that the issue here is that we should listen more to the affected people and we must develop more protocols, guidelines, programmes with the affected people and not exclusively from the expert, professional or public health opinion." (PM07)*

Ownership has implications for both costs and treatment. Given ongoing changes in population demographics, reducing the burden on the healthcare system by involving the wider community provides a financially sustainable solution. Also, given the multicomponent, bio-psycho-social nature of frailty, a purely medical/physical approach to frailty may fail to address some or all of the cognitive and/or social components associated with the condition.

In summary, this theme challenges the role of the hospital and specialists as the dominant force in frailty care. It provides an opportunity for medical professionals, specifically specialists, to share ownership of frailty, certainly with other healthcare professionals in the short term and also to actively engage with the wider community. In doing this, a culture shift in care could be facilitated and older adults empowered to take greater control of their later life journey, which will be discussed next.

A culture shift in care

Participants judged that there was no simple solution to the frailty challenge and that there was no single body responsible for leading a culture change.

> "*It's all stakeholders. There's no one person that owns this. There's no one sector that owns it. There's no one group of professionals that owns it so it's got to be across public sector, a cross-government kind of approach."* (PM03)

Shifts in ownership of frailty would constitute a significant shift in the prevalent models of care. Policy makers were aware that the current model of acute care was not effective in managing complex, chronic conditions such as frailty and that a culture shift was required to adapt to the changing needs of the population.

> *"I think that it is increasingly consensual that our current health care models are not so conducive to looking at this sort of complex cases. I mean you have a lot of,*

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increasingly you hear about, issues about multimorbidity for instance but still our healthcare systems are geared to single chronic diseases." (PM02)"

There was a recognition that frailty and frailty management are complex issues involving many stakeholders and numerous components. This was a view supported by other policy makers who described frailty as a "*puzzle*" (PM01). Participants noted the multiplicity of stakeholders involved in the creation of a 'new' culture and suggested that in order to facilitate change, a multilateral approach to raising awareness, from the 'bottom up' (general public) and the 'top down' (healthcare commissioners) would be necessary.

In terms of delivery of a more appropriate system, policy makers described a model of integrated and person-centred care in which frail older adults are treated as a whole, rather than as a fragmented collection of illnesses. They also described a system that would empower older adults to reduce their dependency on others, and ultimately conserve resources.

"If somebody needs assistance in washing and dressing we tend to enable them, whatever their daily needs but we are not enabling them to make themselves more capable of doing that. I think if we were addressing frailty it would get us to that point and in fact, it might save, eventually, in the long term, some of the costs associated with caring because at least, even a small proportion get self-caring, is still beneficial." (PM01)

There was also a warning by one policy maker that medicalising frailty and singling it out as a clinical syndrome would disrupt recent progress in care integration.

"*I think that one of the biggest challenges and the biggest risks is that if you put this into a frailty box. I think that this has got to be done in the context of this is about older people, this is about later life, this is about people centred integrated care and support. I think if we try to make it something that is different from what we've been talking about for the last ten, fifteen years around chronic disease, we'll fail.*" (PM03)

Supporting this and developing it further was another policy maker's "*salutogenic*" (PM07) perspective addressing cultural norms about health and the way in which contemporary society focuses on the absence of health or the presence of an acute/chronic condition. Within this idea, they described how an experience of frailty could potentially be embraced as a way of opening up a range of possibilities, interactions and opportunities, particularly within the

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community, "*a social prescription*" (PM07). In their thoughts about care integration, they spoke about a concept of citizenship, a social movement, "carezenship" as a marker of an advanced society, an advanced citizenship, one in which citizens take care of themselves (both on a personal and societal level) and learn to value care. However, they acknowledged that this would be a challenge.

> *"We are asking a lot of ourselves to reorient programmes and interventions with a salutogenic approach, and give prominence to people, to the people themselves, rather than the scope of needs that generate demand for services, and professionals to look after needs, and also to create health based on assets, on these resources we all have."* (PM07)

Barriers to a culture shift

Policy makers described an integrated model of care as appealing in theory. They provided some evidentiary support, notably from pilot schemes, but they acknowledged that it would take time and thought to integrate into existing systems.

> "*It's a bit of a long game and I think progress that has been made is now becoming even more challenging with the current fiscal environment. So, yes, we know it's the application of the chronic care model for long term conditions but doing that through a functional, a people-centred, integrated and functional lens, absolutely we know what we need to do, we just need to do it. (*PM03)

This latter extract raises potential barriers to an integrated and truly democratic healthcare system: there is a time element, an acknowledgement that this is a "*long game*" (PM03) and that change management is a lengthy process; there is a need to be mindful of finances and resourcing issues; there is a need to take action, to implement the system or actually "*do it*" (PM03); and there is a need to focus on patients' autonomy.

Despite acknowledging the difficulties and lack of funding for new projects in the current environment of austerity, policy makers indicated that finances and resources were available and could potentially be reallocated to support a different system.

> *"So, can this still be deliverable? The answer is yes but it needs a great deal of commitment, a great deal of fresh thinking to see how we are currently utilising our resources and see how we can change it to fit into this pathway and … we've already*

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got nutritionists, we've already got physiotherapists, we've already got occupational therapists and physical activity experts, but currently the way we utilise them is different and what we need to do is see whether there could be changes in the way they actually deliver their service with frailty as an underlying theme." (PM01)

This extract emphasises the need to do things differently, to think creatively and to *"rewire and use [assets] differently"* (PM03), in order to better manage complex and chronic care needs. There is a sense that change is both possible and necessary, and that resources are available to facilitate this:

"Since 2014 I would say we have had every year sizeable envelopes from different programmes from the [commissioner]. So the finance is available……so there has consistently been money for this even when it's not called, that it's not for frailty." (PM02)

Another challenge for resourcing is the fact that frailty is often subsumed within other remits and is viewed within a subset of many other chronic diseases of older adults. In fact, there was a strong sense from policy makers that frailty could not be viewed in isolation or "*disconnected from the wider conversation about managing chronicity and complexity in care systems*" (PM03) and therefore should not be funded separately. It is important to note though, that policy makers state that a focus on frailty is required.

Cultural acceptance of an integrated care system

The complexities surrounding change management in large systems and institutions, as well as issues of cultural acceptance of a new way of working were described.

"I think this [acute healthcare model] *is a problem, not just in* [region name] *but all over the world…I think it will be a very slow process.…I expect this process will take probably five to ten years before the culture of professionals will be ready because our doctors, our General Practitioners, our specialists and also social care workers are not trained to change their way." (PM05)*

Indeed, the power transfer from senior clinicians to a wider range of potentially less well qualified staff in a truly democratic care pathway, implied in this extract, was an issue raised by a number of policy makers. Policy makers noted that senior clinicians may be reluctant to involve less well qualified people in decision making processes.

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"What is integrated care? What is person centred care? What is joint decision making? …it would, in several systems probably need a radical, a new thinking of… not this, "I'm the doctor, I know what's good for you, this is what you're going to do" but a change in the doctor-patient relationship and also in the relationship among the different health personnel. You know, if suddenly the social carer has the same say in a discussion around a specific patient as the medical doctor." (PM04)

Policy makers described cultural issues of medical hierarchy and physician dominance in health care, where power is exercised through the professional autonomy of doctors. There are issues here about the ability of doctors to treat allied health professionals and other stakeholders, for example carers, as equal counterparts in the care of frail adults. Further, there are issues of trust and reluctance on the part of the doctors to transfer power, knowledge and ownership of frailty management in a more democratic system; equally there may be reluctance on the part of other stakeholders to accept those responsibilities; thus resulting in fractures in care provision. Notwithstanding these cultural challenges, policy makers were optimistic and believed that barriers could be overcome given sufficient time and training.

Several policy makers were keen that any new frailty management system should be woven into a wider network of healthy ageing issues and delivered as a programme styled as "*living well for longer*". (PM03). The aim of this was to standardise approaches to multimorbidity and chronic disease, i.e. to have the same pathway for all, but also to overcome the negative connotations and language associations with frailty.

"*I think we're probably stuck with a fairly negative connotation from frailty, sounds as if it's something that means people are helpless, nothing you can do, whereas if we slip language and put the focus on ageing well, active and healthy ageing, living you know, living more positive fulfilling lives, then people could hang on to that, what's not to like about that?"* (PM03)

Signposting adult care

Stakeholders in the first phase described difficulties accessing care and navigating overly complex care systems. To overcome this, they expressed the need for an official "wellbeing coordinator". This suggestion for a new health visitor style role, as an advocate, monitor and source of information, was not supported by policy makers.

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Some policy makers suggested that the role was unnecessary as the family doctor or GP could act as a care navigator.

"I would like to think that a good General Practitioner, who has good understanding of frailty, can be themselves the coordinator, we don't need a separate person. (PM01)

Others suggested that GPs are already overburdened and that there are potentially more suitable people to take on this task.

"Actually, it doesn't need to be the GP, the GP might not be the best placed person for that individual. It might be the mental health nurse, it might be the social worker, it might be the OT [occupational therapist], *it might be community connector."* (PM03)

Policy makers also raised the idea that new services, such as a wellbeing coordinator should be elective rather than prescriptive, which might also assist in controlling care costs.

"*So, I think the one size fits all is definitely not the way to go and personalised care, where the patient only receives the treatment that she really needs, maybe in the end this would actually be cost effective for the health system if you don't get everything just because a protocol foresees it."* (PM04)

To summarise, the proposed new role of the wellbeing coordinator was not supported. However the policy makers acknowledged that an enabled person in an existing role, a personal *navigator* is required to help older adults and their caregivers to access appropriate services.

Screening for and preventing frailty

Policy makers were receptive to the idea of screening for frailty so long as it initiated a proactive consultative programme of care and interventions, a view which resonated with focus group members in the first phase of research. One policy maker (PM07) made the point that screening was simply another method of "*medicalising*" frailty and categorising a life stage. Despite doubts about the preventability and reversibility of frailty, there was a strong belief in the power of screening as a tool for effectively targeting those most in need of healthcare services and interventions, and directing resources accordingly.

"If you are able to detect this health problem early and to know that you have the right measures to apply them and that they will really make improvements in life expectancy, in quality of life, then the benefit is really there." (PM07).

One participant raised concerns about the viability of frailty prevention interventions in an older, chronically ill population, i.e. whether interventions are cost effective and beneficial.

"*Screening is necessary. Is it viable? Most likely for the system, on balance, yes. Why? The problem of intervention in the case of these people, if we look to the future, must be focused on their specific health needs. So it is good to know which patients they are so we do not undertake unnecessary medical interventions. If a patient comes to a specialist who does not recognise frailty, they will want to cure the patient. So the question is, if frailty cannot be cured, are those interventions necessary from a medical standpoint?"* (PM06)

The perception that frailty is untreatable is also of interest, although this was not shared by all participants. Irrespective, there was an overwhelmingly positive view from policy makers that screening *followed by interventions* are worthwhile:

"I would really only support screening for frailty if it was linked with the kind of interventions that can make a difference. Otherwise, why are we doing the screening programme? It's about human values as much as pounds." (PM03)

Policy makers were also concerned with wider issues, the practicalities of screening and the complexity of screening tools.

"Any tool that is complex or that has multiple steps or requires quite a lot of in depth assessment might be quite difficult to perform as a screening tool, purely because the numbers we would be dealing with are going to be huge. We wouldn't have the resource (PM01)

There was a general consensus that a "*simple and easily reproducible*" (PM01) or "*straightforward*" (PM02) tool was required to minimise the resource and labour implications for health services and key professionals.

The affordability of population screening programmes was not a primary concern. Policy makers agreed that there were ways of reducing screening costs through targeting strategies such as algorithms and e-Health or self-assessment systems. Of more concern were the

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matters of when screening would occur and who would undertake it. One policy maker had a clear opinion that it should not be undertaken by General Practitioners.

> *"and, who would be screening for frailty? You know, the GP? I don't know, is that another thing you want to burden on GPs? Did you speak to GPs about that? You know, we are putting so much on them, you know literally everything is on the GP in this regard, everything."* (PM04)

Policy makers were mindful of screening at "*key transition points*" (PM03) in people's lives: including instances of acute illness, prescription review, bereavement, and moving home/care setting. The view here was that screening and intervening at these critical points can significantly affect the incidence of adverse outcomes such as institutionalisation and dependency. Reverting back to the idea of an integrated and personalised system of care, there was also an understanding that an individual-specific "*care navigator*" (PM03) would be present at the time of screening.

Discussion

The data gathered have enabled us to consider which issues need to be addressed to assist in frailty management, screening and prevention programmes. We identified a *knowledge gap* regarding frailty and the need to raise awareness of frailty and the treatability of frailty throughout the medical profession through improved training and research. Healthcare professionals including the primary healthcare team, require an awareness of frailty and its treatability, as well as guidelines for best clinical practice, an overview of insights from new interventions and practical guidance on how to assess and manage frail individuals. Simultaneously, there is a need to reconsider the current system of 'opportunistic' healthcare professional training on frailty, which may vary dependent on students' clinical placements, to ensure that all new healthcare practitioners develop a full understanding of the experiences of frail older adults. We also identified the need for frailty to be recognised as a clinical syndrome but managed within a broader remit of *healthy ageing* in the community.

Despite evidence to the contrary, our analysis found that some policy makers, as well as other stakeholders, believe that frailty is not preventable or amenable to intervention. Since the effectiveness of any frailty management or screening programme relies on the prioritisation and allocation of resources and labour, this may lead to inequality in service provision across different jurisdictions. Further, there is a danger that screening programmes in these areas

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will classify older adults as frail or pre-frail, identifying those who would benefit from early intervention but then fail to implement appropriate preventative treatments.

Policy makers recognised the difficulties associated with managing frailty and the need to apply creative solutions to better organise and redeploy existing services, resources, skills and knowledge sets to manage complex and chronic care needs.

We noted that policy makers placed value on the development of an integrated and person-centred system of care, involving a care navigator, and while this idea is to some extent in its infancy, there was a strong sense that this was the preferred route. Certainly this system is in line with the Chronic Care Model (30, 31) which has been shown to improve patient care and result in improved outcomes in chronic conditions (32). Indeed, in some countries, this is beginning to happen. For example, in the UK, recent NICE (National Institute for Health and Care Excellence) guidance (33) for healthcare professionals, on the clinical assessment and management of multiple long-term conditions, recommended that a person's goals, values and priorities are established when determining care plans for adults with multimorbidity.

We confirmed the views of previous stakeholders (26) that screening for frailty must have an outcome or specific purpose, and that outcomes are absolutely essential from a human and moral perspective. We have also identified that there must be an individually negotiated, person-centred and transparent care pathway available after screening for all frail older adults and that this pathway must be sufficiently flexible to adapt to individuals' needs, whether those are physical, cognitive or social. Underlying this culture shift in older adult care is the need to empower people to make informed choices about their own health and healthcare, but such empowerment requires high levels of perceived behavioural control (34) and self-efficacy (self confidence in one's own ability to achieve a particular task, e.g., 35, 36). In this case, believing that frailty is preventable and malleable provides the basis for that self-efficacy; the self-confidence to take charge of one's frailty prevention pathway is dependent on the belief that it is possible. (34) Furthermore, self-efficacy requires ownership; older adults must take ownership of their frailty prevention pathway to engage in it as an active agent. This self-advocacy in turn depends upon healthcare providers who are genuinely person-centred and able to enter into the true spirit of concordance, that is, a negotiated consultation which facilitates informed and collaborative decision making. (37) To achieve this, a psychological behaviour change intervention aimed at healthcare providers may be

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useful, to shift their approach from advice giving, which comes naturally to them and has been rehearsed for many years, towards a collaborative consultation which fosters authentic patient empowerment (38) and takes older adults' freedom of choice seriously. From there, person-centred care, concordance, and the phenomenon of "carezenship" (PM07) become a conceivable possibility, albeit a possibility that will require long term focus and systemic investment to achieve.

Strengths and limitations of the study

To our knowledge, this is the first qualitative study with policy makers from six European countries on frailty. There were some differences in the professional roles of the participants, due to both the nature of the policy organisations in their respective countries and their professional background, for example some were clinically qualified while others were civil servants, although all had significant experience of working in frailty related roles. Nevertheless, it was possible to distil information and compare across accounts, which demonstrated a great number of similarities, irrespective of background and/or role. Although the sample was relatively small, it was adequate to deliver the objective of the study and obtain valuable insights into policy makers' perspectives. To further justify our sample size, there are only a few policy makers in senior healthcare positions within the European Commission and at a senior level nationally within the respective countries and thus, as "elites", the potential pool of participants is itself very small. To our knowledge, healthcare research with policy makers at this level is limited. However, authors have described studies with fewer than ten 'ministry' level participants. (39, 40) Further, in terms of data saturation, a sample size of six in a homogenous population has been described as "sufficient to enable development of meaningful themes" (p78, 41) while others suggested that expertise in a topic can reduce the number of participants required in a study. (42) Although data saturation is difficult to define (43) it has come to be associated with the point at which no new information or themes can be gleaned from the data. (41) Whilst we cannot be absolutely sure that no new information would be discovered with additional interviews, the degree of commonality in responses enables us to fully answer our research questions and view our data as "rich, full and complete". (p149, 44)

Conclusions and implications for clinicians and policy makers

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Frailty is a syndrome which crosses traditional medical, discipline-specific boundaries. Our findings recommend a multilateral campaign of raising awareness of the malleability and preventability of frailty which targets health and social care professionals, healthcare policy makers and commissioners as well as older adults themselves. The aim of this would be to shift attitudes about the inevitability of frailty and overcome some of the cultural challenges associated with niche ownership within the healthcare system, but also to support the idea of integrated care for older adults. The policy makers also recognised the need to better signpost older adult services and recommended a personal *navigator* to help older adults and their family caregivers to access appropriate interventions and services: this may be through the primary healthcare team, GP, a social worker or a community volunteer, but the view was that a new role, that of a wellbeing coordinator, was not justified.

Research and Development, Netherlands) and S. Santana (University of Aveiro, Portugal) who were co-responsible for the design and delivery of this FOCUS work package.

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All authors are guarantors and affirm that the manuscript is an honest, accurate, and transparent account of the study being reported, and that no important aspects of the study have been omitted; and that any discrepancies from the study as planned have been explained.

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Appendix 1

Summary

Understanding frailty: meanings and beliefs about screening and prevention across key stakeholder groups in Europe

This interview is to elicit the response of policy and decision makers to a summary of what other people involved in the context of frailty have said about it, with an emphasis on screening, management, personal and care strategies.

Objectives were to explore different stakeholders' understandings of frailty; the meaning of the condition and their beliefs and attitudes towards the malleability of frailty in view of screening and prevention programmes.

Semi-structured focus group and individual interviews were conducted in three EU countries (Italy, Poland, UK) with five groups of stakeholders – frail and non-frail older adults, family caregivers, and health and social care professionals. An inductive thematic analysis was conducted on transcribed interviews.

Four themes were identified:

·   Interdependence between the physical and the psychological in frailty,

·   living with frailty in the social world,

·   the need for a new kind of care,

·   screening for and preventing frailty.

Findings emphasized the need for earlier intervention for frailty prevention services and an integrated approach to frailty care. Central to all stakeholder groups was the significance of psychological components and social environment alongside the physical elements of frailty and frailty prevention, with this identified by many as making the difference between resilience in the context of physical impairment, and dependence and poor quality of life.

The findings concluded that support and care for older adults and their family caregivers needs to be accessible and coordinated. Interventions to prevent frailty need to encompass a social dimension to help older adults maintain a sense of self while also building physical and psychological resilience.

Appendix 2

Questions for Policy Makers:

This is a guide as to the topics that should be covered, but participants are free to add other things they think are important.

1. **What do you understand by the term "frailty"**

   Subordinate questions (to encourage fullness of response if necessary)

   (i)   What do you think are the likely causes of frailty?

2. **To what extent do you think frailty can be addressed in the population?**

   (i)   Do you think there are ways we could prevent people from becoming frail?

   (ii)   Do you believe that frailty is treatable or preventable (malleable)?

   (iii)   Do you think there are opportunities to influence frailty status by means of early identification and management through lifestyle and other interventions?

   (iv)   How can we raise awareness of the malleability of frailty among professionals and across society generally to encourage a cultural shift in views on frailty?

3. **To what extent do you think frailty can be addressed in the population?**

4. **Do you think that screening for frailty in older adults is worthwhile?**

   (i)   What are the barriers to screening as you see them?

   (ii)   What are the benefits to screening as you see them?

   (iii)   In our research, participants raised a number of challenges associated with frailty screening, the form that they suggested, one which was consultative, sensitive, and which leads to personalized care would be expensive for health and social care systems to implement. To what extent do you believe screening for frailty in this manner would be possible?

   - Financially?
   - Practically?

5. **Do you think that a model of acute care is suitable or unsuited to patients with complex needs (i.e. frailty)?**

   (i)   how can care pathways be better organised and delivered in order to ensure that the needs of people with multiple risk factors are fully addressed?

   (ii)   (Prompts: reliable holistic assessment, multidisciplinary care planning, care co-ordination, improving communication between patient, family members and professionals, continuity of care, access to specialists and diagnostics)

(iii)   Participants also made suggestions about how frailty prevention services could be improved to support older adults, e.g. by engaging them in preventative strategies such as stimulating cognitive activity, personalised exercise plans, greater social engagement, in order to build resilience; and by the development of an advocacy service to help older adults and their family caregivers to access services. A care coordinator model or adult health visitor type role was suggested as a bridge between health and social care services. To what extent do you believe that these changes would be possible?

(iv)   What difficulties would you expect if treatments or interventions (e.g., such as exercise training) for frailty were to be introduced more widely? Do you think that is a good idea? What benefits would that have? What might be the problems with that (e.g., costs, resources, implementation)?

6. **What type of legislation, regulation, standards, guidelines or measures do you believe would be required to ensure that a frailty prevention/management system can be fully supported?**

(i)   Who do you believe are the key individuals who make decisions in the areas of frailty care/prevention/management and funding?

(ii)   What do you perceive as the main challenges in translating frailty prevention/management policy to practice?

7. **Is frailty prevention/management a priority for your department?**

(i)   What sort of work is being done by <your department> to ensure that an agenda of care is being implemented to prevent/manage/reverse frailty?

(ii)   Has your work/the work of <your department> influenced legislation, regulations, policy, programming or procedures? If so, where/when/how?

(iii)   Are finances available to specifically address frailty issues?

   a.   If so, how is funding distributed? Centralised vs decentralised? And prioritised?

(iv)   Where is the money spent now?

   a.   Prompts: Care or preventative care?

(v)   Have you involved older adults (frail or otherwise) in your public discussions or policy making?

8. **How can training and Continuous Professional Development be improved to assist in frailty prevention?**

(i) Do you see a role for telecare or internet based programmes in prevention or management of frailty?

(ii) Do you know any e-health services /applications which can be used with benefit by frail patients?

(iii) How can potential services be made accessible for all?

    a. Prompts, e.g., outside office hours, workplaces, community settings, faith centres, digital services, range of languages and culturally acceptable styles.

9. **Is there anything else you'd like to add?**

No	Item	Guide questions/description	
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/ facilitator	Which author/s conducted the interview or focus group?	Detailed on page 5.
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	Detailed on page 5.
3.	Occupation	What was their occupation at the time of the study?	Detailed on page 5.
4.	Gender	Was the researcher male or female?	Detailed on page 5.
5.	Experience and training	What experience or training did the researcher have?	Detailed on page 5.
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	Detailed on page 5.
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*	Detailed on page 5.
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	Detailed on page 5.
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography,*	Detailed on page 5.

No	Item	Guide questions/description	
		phenomenology, content analysis	
Participant selection			
10	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Detailed on page 4.
11	Method of approach	How were participants approached? e*.g. face-to-face, telephone, mail, email*	Detailed on page 5.
12	Sample size	How many participants were in the study?	Detailed on page 2,6 and 7.
13	Non-participation	How many people refused to participate or dropped out? Reasons?	Detailed on page 4.
Setting			
14	Setting of data collection	Where was the data collected? e*.g. home, clinic, workplace*	Detailed on page 5.
15	Presence of non-participants	Was anyone else present besides the participants and researchers?	Detailed on page 5.
16	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	Detailed on page 6 and 7.
Data collection			
17	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Detailed on page 5 and described in full in Appendix 1.
18	Repeat interviews	Were repeat interviews carried out? If yes, how many?	Not applicable.

No	Item	Guide questions/description	
19	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Detailed on page 5.
20	Field notes	Were field notes made during and/or after the interview or focus group?	Detailed on page 5.
21	Duration	What was the duration of the interviews or focus group?	Detailed on page 5.
22	Data saturation	Was data saturation discussed?	Detailed on page 19.
23	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	Detailed on page 6.
Domain 3: analysis and findings			
Data analysis			
24	Number of data coders	How many data coders coded the data?	Detailed on page 6.
25	Description of the coding tree	Did authors provide a description of the coding tree?	Not provided.
26	Derivation of themes	Were themes identified in advance or derived from the data?	Detailed on page 6.
27	Software	What software, if applicable, was used to manage the data?	Detailed on page 6.
28	Participant checking	Did participants provide feedback on the findings?	Detailed on page 6.
Reporting			
29	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each	Detailed on page 6.

No	Item	Guide questions/description	
		quotation identified? e.*g. participant number*	
30	Data and findings consistent	Was there consistency between the data presented and the findings?	Detailed on page 6.
31	Clarity of major themes	Were major themes clearly presented in the findings?	Detailed on page 7 to 15.
32	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Detailed on page 7 to 15.